

# VETERANS HEALTH ADMINISTRATION

H.R.3967: SERGEANT FIRST CLASS HEATH ROBINSON HONORING OUR PROMISE TO ADDRESS COMPREHENSIVE TOXICS (PACT) ACT OF 2022

## PACT Act Research: Some Data Resources to Consider

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Director  
Epidemiology Program  
Health Outcomes Military Exposures  
Patient Care Services



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# Honoring Our PACT Act



The Senate Veterans' Affairs Committee named the bill after **Sergeant First Class Heath Robinson**, who deployed to Kosovo and Iraq with the Ohio National Guard.

After returning home from his last deployment, doctors diagnosed him with an autoimmune disorder and late-stage lung cancer—both associated with burn pit exposure.

SFC Robinson passed away in May 2020. He was 39 years old.

*“Study after study demonstrates Veterans in VA care do better...The PACT Act would be one of the largest substantive health and benefit expansions in VA’s history, comparable in scale and impact to the Agent Orange Act. It would codify many of the ongoing efforts by the department to improve its process for establishment of presumptions of service connection due to toxic exposure, reducing the burden for Veterans and increasing transparency.”*

*-VA Secretary Denis McDonough, May 2022*



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# Acknowledgements

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# Disclaimer

The views expressed are those of the presenter and do not necessarily represent the views or policy of the VA or the U.S. Government.

The presenter has no financial conflicts of interest to disclose.



# Objectives

- PACT Act Research at Health Outcomes Military Exposures (HOME)
- Individual Longitudinal Exposure Record (ILER)
- Registries
  - Airborne Hazards and Open Burn Pit Registry (1.0 and 2.0)
  - Legacy Environmental Exposure Registries
    - Agent Orange, Gulf War, Ionizing Radiation
    - What these sources can and cannot provide
- Millennium Cohort Study VINCI\* Repository
- VA/DoD Mortality Data Repository

\*VA Informatics and Computing Infrastructure



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# Title V & VIII PACT Act Requirements: HOME

- Sec. 502 Analysis and report on treatment of Veterans for medical conditions related to toxic exposure
- Sec. 503 Analysis relating to mortality of Veterans who served in Southwest Asia
- Sec. 504 Study on health trends of Post 9/11 Veterans
- Sec. 505 Study on cancer rates among Veterans
- Sec. 506 Study on health effects of waste related to Manhattan Project on certain Veterans (NASEM)
- Sec. 507 Study on toxic exposures and mental health outcomes (NASEM)
- Sec. 509 Department of VA public website for toxic exposure research
- Sec. 510 Report on health effects of jet fuels used by Armed Forces
- Sec. 801 Epidemiological study on Fort McClellan Veterans



# Individual Longitudinal Exposure Record (ILER)

- **Individual Longitudinal Exposure Record (ILER)**
  - Joint VA/DoD project that compiles available occupational and military environmental exposure (MEE) information.
  - Connects Service Members and Veterans with time, place, unit and/or MEE data.
- **History of ILER**
  - 10 Years in the making
  - Developed in response to Presidential Review Directive-5\* (1998), which directed DoD and VA to develop a joint individual longitudinal exposure record.
  - Roles:
    - DoD: developed systems necessary to create Individual Longitudinal Exposure Record from various DoD database platforms.
      - Addition of Airborne Hazards Registry and Gulf War Registry
    - VA: Health Outcomes and Military Exposures (HOME) is “VA ILER Lead”.

\* <https://irp.fas.org/offdocs/prd-5-report.htm> (fas.org)



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# Individual Longitudinal Exposure Record (ILER)

- **ILER Goal:** Serve as a central portal to provide available occupational and environmental exposure information to help DoD and VA better address exposure concerns for:
  - Service Members and Veterans
  - **Clinicians**
  - **VBA Adjudicators**
  - **Researchers**
- **ILER:**
  - Creates a longitudinal (historic) record of service-related exposures
    - Note: Expectation is that 95% of database entries are “negative” for dangerous exposures
  - Improve medical care for those who have conditions that may be exposure-related
  - Provide exposure data for Veteran disability evaluations and benefits determination
  - Support research and epidemiologic surveillance of exposed cohorts to determine whether deployment-related exposures are associated with post-deployment health outcomes
  - Create exposure cohorts based on location, date, time, unit and/or exposures-agents
  - Improve both medical surveillance and occupational/environmental health surveillance (OEHS) by detecting emerging (or latent) conditions that may be related to exposures







# HOME Environmental Exposure Registries

- Legacy Registries
  - Agent Orange (AOR)
  - Gulf War Registry (GWR)
- Airborne Hazards and Open Burn Pit (AHOBPR)
- Ionizing Radiation Registry (IRR)
- Depleted Uranium Program
- Toxic Embedded Fragments Center





# Reasons for Registries

- Congressionally-mandated registries may help VA understand and respond to health problems more effectively and may be useful for research purposes.
- A registry evaluation is a clinical assessment that is characterized by:
  - a detailed exposure history
  - special diagnostic attention to any symptoms or abnormalities potentially related to military environmental exposures
- Registry evaluations are not part of the disability process, but they are an opportunity to educate Veterans about:
  - The 2022 PACT Act
  - Presumptive conditions
  - The VA disability process



# Exposure Registries

- Strengths
  - Can be a valuable tool for surveillance and epidemiology
    - Can be used for research, but must recognize the limitations
  - May collect information on occupational exposure and disease in large populations
  - May provide an overview of some disease trends
- Weaknesses
  - Significant limitations in the use of registries to draw inferences regarding the presence / strength of an association between an exposure and a health outcome\*
  - Issues include:
    - Self-reporting of an effect
    - Misclassification
    - Recall Bias
    - Self-selection
    - Missing data
    - Large populations: Studies may lead to statistically significant but not clinically significant results

\*National Academies Press: Assessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry, 2017.

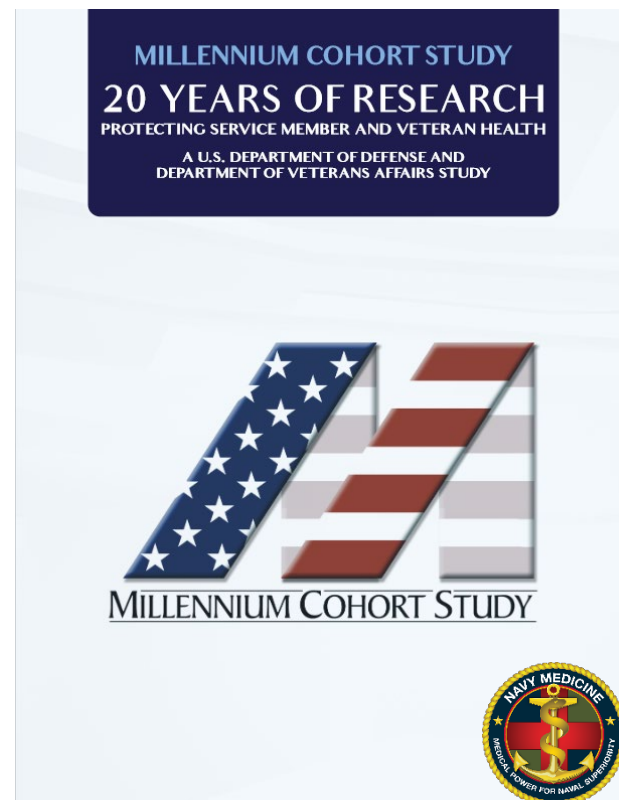
# Airborne Hazards and Open Burn Pit Registry (AHOBPR)

- Present AHOBPR (1.0)
  - A web-based registry launched in 2014.
  - Lengthy self-report questionnaire addressing many domains of military service, deployment and exposures, behavioral risk factors, symptoms and disease and more.
  - >380,000 participants
  - Data requests for research (POC in Resources)
- AHOBPR Redesign: Future State (AHOBPR 2.0)
  - Passive inclusion of all who served in covered countries and currently eligible for AHOBPR 1.0
  - Comprehensive roster will support surveillance and research
  - Supported by Under Secretary for Health (USH)
  - Launch date expected late 2023
  - IT framework, policy development, data acquisition in process
  - Full details regarding content and access coming soon



# Millennium Cohort Study Overview

- Largest and longest running military cohort study
  - Initiated July 2001 (pre-9/11)
  - Planned to continue until 2068
- >260,000 military personnel enrolled between 2001-2021
  - All Service branches and components (Active, Reserve, National Guard)
  - Women and other underrepresented groups oversampled
- 58% of participants have separated from service (2022)
- Research findings inform policy and programs



[\(Link to Report\)](#)



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# CSP 505 Millennium Cohort Study

- *PI* Dr. Ed Boyko, VA Puget Sound
- Supported by an Interagency Agreement (IAA) and Data Use Agreement (DUA)
  - Bilateral data exchange
  - CSP study structure supports collaborative research projects
- To facilitate VA investigator access to MCS data, CSP has developed a repository in VINCI: CSP #505-R: Millennium Cohort Research Data Repository (CSP #505-R)
  - Received full VA Puget Sound IRB approval on 2/2/2023
  - Will make MCS Survey, DMDC, and MDR data available on VINCI for VA investigators to merge with other VA data
  - Research requests will require approval on Data Access Request Tracker (DART) and by the CSP #505-R Scientific and Ethics Oversight Committee (SEOC) before accessing data
- This repository is still in development and not yet available
- POCs: Please see Resources slides



# National Mortality Data: National Death Index (NDI)

- A centralized database of death certificate data from each state and territory's vital statistics office
- Maintained by the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), per agreements with States
- Through an application process, NDI data are available from CDC, with costs based on search size and attributes, for medical and health research
- Death records are added to the NDI annually, final data is available ~12 months after the end of each calendar year
- Authoritative source for **date** and **cause of death** information nationally—considered the “gold standard” of US mortality databases

# VA and DoD Mortality Data: Mortality Data Repository (MDR)

- Established in 2012 as part of VACO suicide surveillance
- Extended the ongoing VA NDI searches for VHA patients, which began in 2007
- VA and DoD collaboration that supports assessments of all causes of mortality
- Comprehensive cause-specific mortality repository for Veterans, Service members, and other VA users
- Includes:
  - records of over 20.6 million deaths from 1979-2020
  - date, cause, and state of death from NDI
  - date of birth, sex from VA/DoD administrative sources





# VA-DoD and the NDI Data Acquisition Process

- VA and DoD jointly compile an annual search list of all identified persons with military service and/or VA service use history
  - Combines data from VA administrative sources/patient records, service era rosters, and DoD personnel records
- NDI returns all possible matching records
- VA and DoD use “true match” algorithms to identify the best match for each record, based on established VA protocols
- Results maintained as the **Mortality Data Repository (MDR)**



# Sources to Consider

QUESTIONS?

[aaron.schneiderman@va.gov](mailto:aaron.schneiderman@va.gov)



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# Sources to Consider

## RESOURCES



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Accredited and available to VA Employees on TMS  
and Community Providers on [www.train.org](http://www.train.org)

## WRIISC-HOME Webinar Series

- Twelve (12) webinars offered annually each fiscal year to support best practices for the ongoing needed up-to-date science and information providers require to adequately respond to the large numbers of returning Veterans who have exposure concerns.

## WRIISC-HOME Military Exposures Clinical Briefs Series

- Thirty (30) minute knowledge-based interview-style occupational group conversations in partnership with the Office of Primary Care, to support the mission of improving health care and benefits for Veterans with military exposure concerns and VA staff endeavors in carrying out the PACT Act.

## WRIISC-HOME Accredited Collections

- Provider directed education in post-deployment health focused specifically on 1) Chronic Multi-Symptom and Gulf War Illness, 2) Exposure Related Concerns especially those related to Airborne Hazards and Burn Pits and 3) Integrative and Functional Medicine; each a key component of whole health and personalized patient driven care.

## Veterans' Health Matters Podcast Series

- Twenty (20) minute conversations offering clinicians, Veterans and caregivers information on post-deployment care and tools on effective patient-provider communications.

2023 Webinar Series



To access this education and more,  
visit: [WarRelatedIllness.va.gov](http://WarRelatedIllness.va.gov)

# A Proud Partnership between the Dept of Veterans Affairs & American College of Preventative Medicine (ACPM)

**Level 1 Certification – Available Now**  
**Level 2 Certification – Coming Soon**

<https://www.acpm.org/Education-Events/Military-Environmental-Exposures-Certification>



**Why should providers become certified in Military Environmental Exposures?**

Over **1/3** of Veterans are concerned about military exposures

Veterans **Expect** VA Providers to know about military exposures

VA providers **Need** tools to respond to military exposure concerns.



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# VA MOBILE EXPOSURE-ED APP

- For health care providers
- Search for military-related exposure information, as well as VA's programs and policies
- Get tips on communicating risk to patients
- Print or email tailored information for patients during or after the visit
- Locate VA facilities
- Available for free on Android and Apple devices
- Download at: <https://mobile.va.gov/app/exposure-ed>
- View the training video at: <https://mobile.va.gov/training/exposure-ed>



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# Individual Longitudinal Exposure Record (ILER)

- [VA ILER and Exposure Portal for Benefits and Epidemiology - Home \(sharepoint.com\)](https://dvagov.sharepoint.com/sites/VACOVEOVIBE)  
<https://dvagov.sharepoint.com/sites/VACOVEOVIBE>



# Legacy Environmental Exposure Registries

## Agent Orange Registry and Gulf War Registry

### Environmental Health Registry Evaluation for Veterans - Public Health

<https://www.publichealth.va.gov/exposures/benefits/registry-evaluation.asp>

For any questions, concerns, and requests for consultation, please contact Irvine Armand-Gibbs [Irvine.Armand-Gibbs@va.gov](mailto:Irvine.Armand-Gibbs@va.gov)



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# Airborne Hazards and Open Burn Pit Registry

AIRBORNE HAZARDS AND BURN PITS  
**CENTER OF EXCELLENCE**



**Airborne Hazards  
and Open Burn  
Pit Registry**

Recognizing that data from the Airborne Hazards and Open Burn Pit Registry (AHOBPR) are a rich resource for the scientific community, VA's Health Outcomes Military Exposure (HOME) and the Airborne Hazards and Burn Pits Center of Excellence (AHBPCE) are working to expand access to AHOBPR data while ensuring the privacy and confidentiality of Veterans' data. These efforts are consistent with VA's strategic priority of "putting VA data to work for Veterans".

For any questions, concerns, and requests for consultation, please contact [vhaeasairhazardscoe@va.gov](mailto:vhaeasairhazardscoe@va.gov)



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# CSP 505 Millennium Cohort Study

- CSP #505 website:  
[CSP #505: Millennium Cohort Study - Seattle Epidemiologic Research and Information Center \(ERIC\) \(va.gov\)](#)
- Current process to request access to data:  
[CSP #505: Millennium Cohort Study - VA Cooperative Studies Program \(CSP\)](#)
- POCs  
Shauna Frank ([Shauna.Frank@va.gov](mailto:Shauna.Frank@va.gov)), CSP #505-R Project Manager  
Lynne Liu ([Lynne.Liu@va.gov](mailto:Lynne.Liu@va.gov)), CSP #505 Project Manager

Information about the Millennium Cohort Study  
[millenniumcohort\\_20\\_year\\_report.pdf](#)

# Mortality Data Repository References

- NDI Fact Sheet:  
[https://www.cdc.gov/nchs/data/factsheets/factsheet\\_ndi.pdf](https://www.cdc.gov/nchs/data/factsheets/factsheet_ndi.pdf)
- VA MDR Flyer: [MDR Flyer, from VHA Intranet](#)
- VA Administrative Summary, VA Applications to Board of Governors:  
[MDR Administrative Summary FY23 Q1](#)
- 2022 Veteran Suicide Surveillance: Methods Summary:  
<https://www.mentalhealth.va.gov/docs/data-sheets/2022/2022-National-Veteran-Suicide-Prevention-Annual-Report-Methods-Summary-FINAL-508.pdf>
- 2022 National Veteran Suicide Prevention Annual Report:  
[https://www.mentalhealth.va.gov/suicide\\_prevention/data.asp](https://www.mentalhealth.va.gov/suicide_prevention/data.asp)
- For more information or to receive the MDR application materials, please contact: [VHACANMDRDataRequests@va.gov](mailto:VHACANMDRDataRequests@va.gov)



# VA ORD Military Exposures Research Program (MERP)

The VA Office of Research and Development (ORD) has established the Military Exposures Research Program (MERP), which seeks to advance military exposure assessments and to understand the effects of military exposures on Veterans' health outcomes to inform care and policy.

The following two slides present an outline of the MERP Organizational Structure and types of Merit Research opportunities available and expected.

RFAs can be found at the Office of Research & Development, RFAs and Program Announcements, ORD Intranet site for further details:

<https://vaww.research.va.gov/funding/rfa.cfm>

Additional MERP RFA opportunities are expected.

If you have any questions, please direct them to Dr. Karen Block at [Karen.Block@va.gov](mailto:Karen.Block@va.gov) or [MERPAdminCORE@va.gov](mailto:MERPAdminCORE@va.gov)



# VA ORD Military Exposures Research Program (MERP)

- **MERP Mission:**

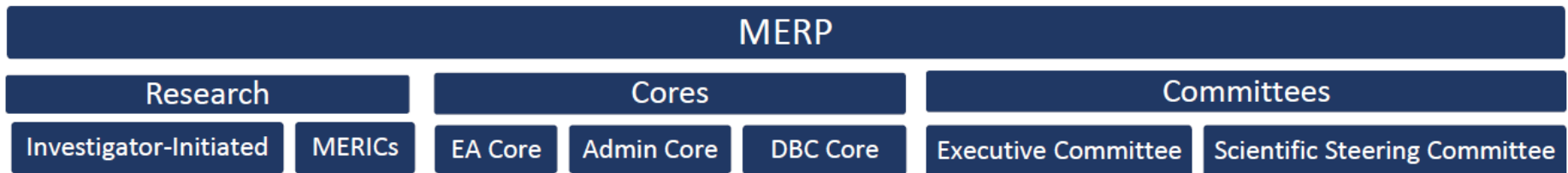
The VA Military Exposures Research Program seeks to advance military exposure assessments and to understand the effects of military exposures on Veterans' health outcomes to inform care and policy.

- **MERP Definitions:**

- **Military exposures** are defined as toxic agents, singly or in combination, incurred through military service (Deployment, Occupation, or Garrison).
- **Exposure assessment** refers to identifying and quantifying toxic agent(s) to which a Veteran was exposed during military service.

- **MERP Organizational Structure**

Leadership	Description
<b>Director</b>	The Director of MERP is an employee of VHA Office of Research & Development (ORD)



# VA ORD Military Exposures Research Program (MERP)

Merit Research Type	Description
<b>Investigator-Initiated I01</b>	VA eligible, rigorous- and evidence-based research that supports the MERP mission.
<b>Program-Directed IC50: Military Exposure Research Innovation Centers (MERICs)</b>	<p>High impact and innovative, rigorous and evidence-based, interdisciplinary research projects that strategically support key priority needs within the MERP mission.</p> <ul style="list-style-type: none"> <li>MERICs encompass 3-4 scientific <b>studies</b> overseen by an interdisciplinary team: Director (PI), program manager, and co-leads while utilizing MERP Core infrastructures and subject matter experts.</li> </ul>

Core Type	Description
<b>Administrative Core (Admin Core)</b>	The Administrative Core will facilitate in guiding MERP goals and ORD regulatory, and policy needs to MERP stakeholders and serve as a liaison among MERP stakeholders.
<b>Data and Biorepository Commons Core (DBC Core)</b>	The mission of the Data and Biorepository Commons Core is to fill MERP programmatic gaps with a focus on building and facilitating knowledge and access to trusted military-exposure data and biospecimens for Military Exposure Research.
<b>Exposure Assessment Core (EA Core)</b>	The mission of the Exposure Assessment Core is to fill MERP programmatic gaps with a focus on enhancing investigator awareness and access to available toxicology relevant-tools and resources to improve exposure characterization.

Committee Type	Description
<b>Executive Committee</b>	The Executive Committee will be responsible for programmatic oversight.
<b>Scientific Steering Committee</b>	The Scientific Steering Committee will be responsible for scientific oversight.



# Some Recent Publications

Woskie, Susan R. PhD<sup>1</sup>; Bello, Anila ScD<sup>1</sup>; Rennix, Christopher ScD<sup>2</sup>; Jiang, Lan MS<sup>3</sup>; Trivedi, Amal N. MD, MPH<sup>3,4</sup>; Savitz, David A. PhD<sup>5</sup>

*Burn Pit Exposure Assessment to Support a Cohort Study of U.S. Veterans of the Wars in Iraq and Afghanistan*

[Journal of Occupational and Environmental Medicine \(\):10.1097/JOM.0000000000002788, January 11, 2023. | DOI: 10.1097/JOM.0000000000002788](https://pubmed.ncbi.nlm.nih.gov/36728333/)

<https://pubmed.ncbi.nlm.nih.gov/36728333/>

Garshick, Eric; Blanc, Paul D.

*Military deployment-related respiratory problems: an update*

[Current Opinion in Pulmonary Medicine 29\(2\):p 83-89, March 2023. | DOI: 10.1097/MCP.0000000000000946](https://pubmed.ncbi.nlm.nih.gov/36597757/)

<https://pubmed.ncbi.nlm.nih.gov/36597757/>



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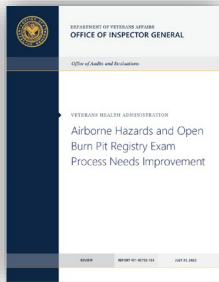
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# Drivers for Redesign



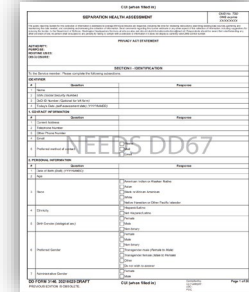
VA OIG Report  
July 21, 2022



PACT Act  
August 10, 2022



NASEM Report  
October 14,  
2022



Separation Health  
Assessment (SHA)

A Unique Chance for a Do-Over – Recommendations for Airborne Hazards and Open Burn Pit Registry (AHOBPR) Improvement

- ❖ VA Office of Inspector General Report on AHOBPR Examinations (2022)
- ❖ National Academies of Sciences, Engineering, and Medicine Reports (2017 and 2022)
- ❖ DS Logon – AHOBPR is behind the Department of Defense's firewall; not Veteran-centric
- ❖ PACT Act provisions and other legislative requirements function as both foundation and driver
- ❖ Separation Health Assessment (SHA) and Separation History and Physical Examination (SPHE)
  - Provide an examination closer to the time of exposure and can be monitored for changes in health over time



# Major Redesign Components

## Automatic Registry Inclusion

Secure the entire Defense Manpower Data Center (DMDC) roster of deployed Veterans and Service Members to the Southwest Asia theater of operations from August 2, 1990 to August 31, 2021. This database will include demographic and deployment information similar to the Karshi-Khanabad (K2), Uzbekistan roster.

- Cross-reference against known VA and DoD databases supporting the population: original AHOBPR, DoD's Gulf War Oil Well Fire Smoke Registry, and Individual Longitudinal Exposure Registry (ILER)

## Elimination of Pain Points: Improvement of Customer Service

- ✓ Remove Utilization of the Problematic DS Logon, a Secure Identity Credential
- ✓ Eliminate the Lengthy Entry Questionnaire – 144 questions
- ✓ Enhance the Registry Exams process as follows:
- ✓ The optional AHOBPR evaluation (done for research purposes and not for care or treatment of claims) will no longer be offered, but a military environmental exposure assessment by their primary care provider is available as usual for any concerns
  - Eligible population can request a Toxic Exposure Screening (TES) assessment from their VA clinician
  - Those not in VA health care can get a virtual exposure assessment from VET-HOME.
  - Pending legacy registry exam requests will be honored till completion
  - Use of Separation Health Assessments (SHAs) and Separation History and Physical Examinations (SPHEs) will provide an exam closer to time of exposure

## Sunset of Legacy Registry

- ✓ Close original AHOBPR enrollment beginning September 1, 2021, the day after the US departure from Afghanistan on August 31, 2021.
  - Those who deployed to the current AHOBPR area of eligibility from September 1, 2021 forward cannot join the AHOBPR Version 2 but can still join Version 1 while this program is active
  - Rationale: The end of combat operations; burn pits have been effectively phased out.



## AHOBPR: Eligibility

- A Veteran or Service member who deployed to:
  - Southwest Asia theater of operations at any time on or after August 2, 1990, and/or
  - Afghanistan or Djibouti on or after September 11, 2001, Uzbekistan, Syria and Egypt added in 2022, and or
  - Airspace and seas in the area.



Eligibility is outlined [Public Law 112-260](#), *Dignified Burial and Other Veterans' Benefits Improvement Act of 2012*.

